



Bioethics Review

The Scholl Institute is a nonprofit, Judeo-Christian organization that addresses bioethical issues including euthanasia, (physician-assisted-suicide) the withholding or withdrawing of food and water from non-dying patients, brain death, organ transplantation, genetic engineering, and rights of disabled or mentally ill persons.

END OF LIFE CARE: WHAT SHOULD I ASK MY LOCAL HOSPICE?

The focus of hospice programs is not curing the underlying lethal disease, but caring for the person's physical, emotional and spiritual needs while working to control pain and discomfort during his/her last days.

"Healing a person does not always mean curing a disease."

These words of hospice founder, Dr. Cicely Saunders, form the foundation for the hospice concept. Beginning in Great Britain in the 1960s, the modern hospice movement has grown enormously over the last two decades. Today, approximately 2,800 hospices exist in the United States alone.

The hospice concept is a positive, available choice for end-of-life care. It's also a popular choice. In 1995 alone, the National Hospice Organization estimated that 390,000 patients were served by a U.S. hospice.⁽¹⁾ With the intensifying public battle over assisted suicide--and with hospice programs receiving attention as an alternative to assisted suicide--the number of patients served by hospice is likely to increase dramatically.

Hospice care is different from traditional medical care. With over 90 percent of such services being provided in the patient's home, hospice programs *"seek to enable patients to carry on their remaining days in an alert and pain-free manner, with symptoms under control, so that those last days may be spent with dignity, at home or in a home-like setting, surrounded by people who love them."*⁽²⁾ Most patients in hospice care have received a "terminal" diagnosis and are seeking assistance in living the last days or months of their lives.

The focus of hospice programs is not curing the underlying lethal disease, but caring for the person's physical, emotional and spiritual needs while working to control pain and

discomfort during his/her last days. Before considering hospice, therefore, a determination must be made that there remain no effective treatments for the person's underlying lethal disease or that all remaining treatments for such disease are gravely burdensome for the person or otherwise require heroic virtue (extraordinary means).

Hospice is a concept which offers a stark contrast to the work of Jack Kevorkian. However, it is important for patients and families to ask educated and detailed questions of their local hospice before admittance. These questions will help assure that the patient is receiving the best possible care given his/her individual condition and circumstances. They also will help allow you to clarify your concerns that the equal worth and dignity inherent in the patient's life is respected at all times.

Here are some questions you should ask your local hospice:

- Does the hospice have a specific policy on "palliative care"? How does this particular hospice define "palliative care"?

Palliative care is essentially "comfort-oriented" care. Instead of working on curing the underlying lethal disease, hospice is intended to help patients live well until death by employing good palliative care. Advances in pain management and drugs such as morphine are routinely used by hospices to keep patients comfortable.

Some hospices, however, may consider such things as food and water to be "extraordinary means." For some, "palliative care" may include assisted feeding (feeding tubes), while others may have official policies that do not allow any assisted feeding. Decisions regarding assisted feeding, however, must be based on the patient's individual condition and circumstances; if assisted feeding is ordinary means, as that term is properly understood⁽³⁾, it should be

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provided. It is crucial, therefore, to find out exactly what your local hospice's policy on assisted feeding is--otherwise you or your loved one may have to fight to be sure that food and water are provided.

- Does the hospice advocate or refer for assisted suicide?

Although the positions of national hospice organizations are against assisted suicide, the battle is raging within the grassroots hospice community on the subject. Evidence of this disagreement within the ranks is documented in *The American Journal of Hospice and Palliative Care* where two local hospice leaders proclaimed that "*Hospice is not for everyone!*" and called for the legalization of assisted suicide.⁽⁴⁾ Pro-euthanasia organizations, such as the Hemlock Society, also are lobbying national hospice organizations to change their anti-assisted suicide stand. One hospice leader even claimed to the media that a national hospice organization is becoming "*more receptive*" to the idea of legalized assisted suicide.⁽⁵⁾ It is crucial to avoid any hospice that participates in any way in assisted suicide or decisions to hasten death, including referral.

With the Supreme Court's 1997 ruling essentially allowing states to decide whether assisted suicide should be legal or illegal, this question will become more of an issue as states increasingly are pressured to legalize assisted suicide.

- Will the hospice put your "*right to life*" above your "*quality of life*"?

While the National Hospice Organization opposes assisted suicide, its treatment policy does emphasize the patient's "*quality of life*."⁽⁶⁾ Emphasis on the patient's "*quality of life*" can lead to euthanasia (an act or omission that of itself or by intention causes death) when people in decision-making authority decide that a person's "*quality of life*" is so "*low*" that the person would be better off dead than living.

A diagnosis of "*terminal*" does not justify either a lethal dose of drugs or an omission of ordinary means of treatment and care. You must make sure that medical treatment and care decisions continue to be based on the patient's individual condition and circumstances, with respect for the absolute, inherent sanctity and quality of his/her life.

- Will my hospice allow my primary treating physician to follow my treatment once I'm in the hospice program?

It is very important to choose one's physician carefully and

wisely. A physician who respects the sanctity of human life, and who is familiar with the patient and the patient's history and current condition, can help ensure quality hospice care.

Every hospice is different.

There is no national criteria for what the specific policies of a hospice must be. As a matter of fact, many states do not even require hospices to register with the state or obtain a license. This makes it even more important that you discuss these crucial issues with the providers at the specific hospice at which you or a loved one may be placed. For further help in evaluating hospice care, consult the resources list below.

Hospice care at the end of life can be a blessing--not only for the patient, but for the families involved as well. Asking good questions and making your desires well-known will assist you in assuring quality, moral care for you or a loved one during the last days of life.

References

- (1) Statistics obtained from the National Hospice Organization Fact Sheet, 1901 N. Moore St., Suite 901, Arlington, VA 22209.
- (2) Hospice Foundation of America, 777 17th St. #401, Miami Beach, FL 33139.
- (3) For further discussion of ordinary-extraordinary means, consult *Do I Have to Spend My Last Days Hooked Up to Machines Against My Will?* and *When I'm in the Hospital, Are Food and Water "Medicine"?*
- (4) *The American Journal of Hospice and Palliative Care*, May/June 1997, pages 130-33.
- (5) "Forum Addresses Assisted Suicide," UPI news article, April 26, 1996.
- (6) "Hospice Services Guidelines and Definitions," National Hospice Organization, 1901 N. Moore St., Suite 901, Arlington, VA 22209.